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PERCEIVED BARRIERS TO DISCUSSING END OF LIFE CARE PLANNING

A Major Paper Presented

by

Karen Bouchard

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PERCEIVED BARRIERS TO DISCUSSING END OF LIFE CARE PLANNING

by

Karen Bouchard

A Major Paper Submitted in Partial Fulfillment

of the Requirements for the Degree of

Master of Science in Nursing

in

The School of Nursing

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Abstract

Advance care planning (ACP) related to end of life (EOL) care is an often neglected area in primary care. Nurse care managers (NCM's) are in a unique position to initiate earlier conversations about illness management and patient preferences regarding end of life so patients have the opportunity to make choices and have their wish known while they are still cognitively independent. The purpose of this quality improvement project was to identify barriers to discussions about end of life care with patients in clinical practice. Six NCM's participated in two focus groups to identify perceived barriers for end of life care discussions and to identify potential solutions to those barriers. Barriers identified included: patient/family factors, organizational factors, and provider related factors. NCM solutions identified included patient related interventions such as normalizing and routinizing EOL/ACP discussion reviewing choices at all ages annually. Organizational solutions recommended include making EOL care discussions a quality measure and training all office staff to support culture change. Provider related recommendations included providers completing their own advance directive as a way to lead the way for patients. Implications for education, practice, policy, and research are identified.

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Perceived Barriers to Discussing End of Life Care Planning

Background/Statement of the Problem

In primary care clinical practice, an area most neglected is the use of end of life care planning for chronic and end stage disease management (Meyer, 2012). Research suggests that healthcare providers may not be doing an adequate job addressing end of life care associated with chronic illness for patients (Meyer, 2012). Palliative care or hospice programs are typically not utilized until a patient is very close to death with weeks to days remaining. Often at the end of life, many people do not receive the care choices they would have made for themselves if they could have had the chance to decide how they wanted to spend their last days earlier in the care process (Dixon & Knapp, 2018). Patients and families often are not able to take advantage of the opportunity for additional support and services administered by a multi-disciplinary team with the mission of easing pain and distress, promoting comfort, and providing support for chronic illness at end of life. Patients with chronic illnesses, high utilization of services, as well as co-morbidities, frequently experience exacerbations toward the end stage of chronic disease, spending much of their time in the hospital. Repeated admissions for incurable problems or symptoms tend to make patients more debilitated, leading to a decline in overall health and functional status with decreasing quality of life (Meyer, 2012). With subsequent admissions, patients are at increased risk for complications and often rapidly decline due to the downward trend of their disease process (Myer, 2012).

Promotion of quality of life for dying individuals and their survivors is integral to the Healthy People 2020 national goal established to increase quality to the remaining years of life. In viewing end of life from a public health perspective, Miller and Ryndes (2005) identified two key concepts that are characteristics of quality of life: one is multi-

dimensional and includes physical, social, psychological and spiritual dimensions; the other is uniquely subjective and only truly be determined by the patient (Miller & Ryndes, 2005). The authors found that while death from chronic terminal illness is common, patients and their families often experience negative consequences of a long period of terminal decline for which our healthcare system does not adequately address these challenges. Since many Americans are living longer with chronic illnesses, they are now faced with a long and often uncertain path toward death and associated difficulties for dying individuals and their families ranging from physical and emotional distress to financial ruin (Miller & Ryndes, 2005). The authors noted that it is important from the public health perspective that quality end of life care in communities continue to be monitored and that promotion of higher quality of life for dying individuals be at the forefront of end of life care.

The need for a paradigm shift related to the trajectory of chronic disease and end of life care was discussed by Holman and Lorig (2000). The authors argue that chronic disease has become the major medical problem and that patients must become partners in their health care decision making. In the United States (U.S.), chronic disease is the major cause of disability and is the main reason why people seek health care (Holman & Lorig, 2000). The authors noted that with chronic disease, a patient's life is transformed with variations in patterns of illness and treatments with unknown outcomes that create uncertainty about prognosis. The researchers found that during the past 50 years, as prevalence of chronic disease has risen, health care practices have attempted to respond to that demand to deliver more efficient and effective care, but that response is still in the early stages (Holman & Lorig, 2000), including for end of life care for this population.

The chronic illness trajectory which is associated with exacerbation symptoms and negative death experiences, emphasize the need for increasing recognition of patient-centered care programs such as community based palliative care. Palliative care is defined as “an approach that improves quality of life for patients and families facing life threatening illness through management focused on relief of pain and distressing symptoms” (World Health Organization [WHO], 2018). Palliative care also encompasses psychological and spiritual care as part of the program support system. Kamal, Currow, Ritchie, Bull, and Abernethy (2013) described reasons for supporting the palliative care approach through community-based palliative care (CPC) programs that helps support the individual with chronic end stage illness while at the same time helping to symptom manage their care in the home setting (Kamal et al, 2013). The goal for CPC programs is to improve the quality of remaining life with supportive care. The authors observed that early identification and participation in community based palliative care programs helps patients and families with coping and coming to terms with end of life as a normal part of life (Kamal et al, 2013).

Cohn, Corrigan, Lynn, Meier, Miller, Shega, and Wang (2017) contribute to the discussion about end of life care for the large numbers of those living with chronic illness, reporting that an estimated 45 million Americans are living with one or more chronic conditions that limit self-care and are likely to worsen over time. While this only represents 14 percent of the population, those with serious chronic illness account for 56 percent of all health care expenditures, almost \$1 trillion dollars (Cohn et al., 2017). The authors stated that in order to care for this population, more palliative care programs are needed as they are patient/family centered, allow for shared decision making in support

of patient goals, and provide team based comprehensive coordinated care in accordance to the social determinants of health. The authors concluded that providers, patients, and family members benefit from having crucial conversations about serious and chronic illness management with goal based care plans that include symptom management plans as well as the patient wishes for future care (Cohn et al., 2017).

Nurse Care Managers (NCM's) have a unique knowledge base to use towards care coordination among the multi-disciplinary team for advanced care planning education (Meyer, 2012). Through the use of advanced care planning for EOL care, patients can make their wishes known in writing for both their healthcare providers and family to follow while they are still able to make their own decisions. ACP is essential for reducing emotional, social, and financial burdens that people associate with complex healthcare decision making (Dixon & Knapp, 2018). NCM's could greatly impact change in clinical practice on these negative outcomes by promoting important discussions and providing education on advanced care planning. (Dixon & Knapp, 2018).

Hebert, Moore, and Rooney (2011) present the nurse care manager within primary care practices as a vital advocate for patients at the end of life. Currently, this is not a standard practice, but a shift in that direction is needed to bring end of life care and advanced care planning discussions into routine primary care. The NCM would be an advocate to not only recognize the time to incorporate end of life care information and support when someone is diagnosed with one or more chronic illness, but to bring about change in the care delivery system (Hebert et al., 2011). NCM's work within primary care settings and are uniquely positioned to be champions promoting end of life care

discussions and advanced care planning. NCM's can educate and work with primary care practices to incorporate these needed discussions as part of managing chronic illness.

Many clinicians may not know how to respond to difficult questions or emotions that their patients' face when facing end of life. This is a significant barrier that needs to be overcome (Hebert et al., 2011). Hebert et al. (2011) notes that NCM's and providers alike face challenges to their awareness of their own personal and cultural beliefs which impact their ability to have these often difficult conversations with their patients about EOL care (Hebert et al., 2011). The authors assert that providers may not have developed the skills through their career training to be more clinically prepared to have these types of conversations which tend to be emotionally charged.

The purpose of this quality improvement project was to identify barriers that nurse care managers face when discussing end of life care with patients during their clinical practice. The practice of EOL care discussions is often not part of routine care. Focus groups with NCM's to help to identify perceived barriers in coordinating end of life care and to promote advanced care planning were conducted. Research is lacking on barriers for health care professionals to provide ACP support and feasible models to implement evidence based EOL conversations (Dixon & Knapp, 2018).

Literature Review

A literature review was conducted using databases to explore nurse care managers' perceived barriers to end of life care discussions searching peer reviewed journals through CINAHL, PubMed, and MEDLINE. Search terms used were palliative care, end of life care, advanced care planning, hospice care, chronic illness, disease management, and patient and provider discussions. Peer reviewed literature was searched between the years 2003 and 2018 using only English language.

Quality of Life at End of Life

A prospective longitudinal cohort study of advanced illness patients by Zhang, Nilsson, and Prigerson (2012) was performed from 2002-2008 at multiple inpatient facilities across the United States. Three hundred ninety-six patients and their informal caregivers were followed from enrollment in the study to death for a median of 4.1 months duration to determine factors impacting on quality of life in the last week of life. According to this, the following nine factors, in order of rank, were noted by the authors to explain variance in quality of life: 1) Intensive Care Unit (ICU) in the final week of life (4.4% of variance); 2) hospital death (2.7% of variance); 3) patient worry (2.7% of variance); 4) meditation or religious prayer (2.5% of variance); 5) site of cancer care (1.8%) of variance; 6) feeding tube use in the final week (1.1% of variance); 7) pastoral care within the hospital (1% of variance); 8) chemotherapy within the final week (0.8% of variance); and 9) patient-physician therapeutic alliance at baseline (0.7%). While the majority of factor variance was noted by the authors to remain unexplained, the study found that being hospitalized, being in the ICU, and having curative interventions such as chemotherapy and tube feedings predicted lower quality of life. Patients who perceived less worry, prayed or meditated, were visited by pastoral services, and had therapeutic

relationships with their healthcare providers demonstrated higher quality of life measures. These quality of life (QOL) measures included adequate pain and symptom management, effective communication with providers, treatment preferences with provider supporting patient choices (Zhang et al. 2012).

Chronic Illness and End of Life

According to a semi-structured literature review by Vogeli, Shields, Lee, Gibson, Madu, Weiss and Blumenthal (2007), patients with multiple chronic conditions (MCC) are a large and growing segment of the U.S. population. Currently in the U.S., 60% of adults have a chronic illness and 40 % of adults have two or more chronic illnesses (Centers for Disease Control and Prevention [CDC], 2018). Consideration of end of life issues in those with chronic illness is critical to fully understand and to provide strategies for this public health issue. The authors reviewed one hundred twenty-three peer reviewed publications which focused on the prevalence, outcomes, costs, and patient care management issues of those living with chronic illness. They reported that chronic disease is the leading cause of death and disability in the U.S. with 133 million Americans or 45% of the population having a chronic illness which significantly contributes to the \$3.3 trillion spent annually on health care in this country (National Institute of Health [NIH], 2018). The authors also noted that the health consequences of patients with multiple chronic conditions have a strong relationship to functional impairment at earlier ages than their counterparts who do not have multiple chronic conditions (Vogeli et al., 2007). The review found that the growing numbers of patients with multiple chronic conditions present serious challenges to the healthcare system since this vulnerable population is often in need of complex care and often unable to manage

the care themselves (Vogeli et al., 2007). Those living with MCC are particularly vulnerable to suboptimal quality of care thus making care coordination more difficult (Vogel et al, 2007).

When individuals are diagnosed with life threatening conditions, they are often concerned about their prognosis including how long they have remaining and what their experience will be. A review of twenty-four clinical research articles by Murray, Kendall, Boyd and Sheikh (2005) identified dying trajectories that described patterns of dying when a patient is given a projected death timeframe with minimal medical intervention options. The research noted that the course of death due to chronic illness is progressive with expected organ failure, frailty, or loss of independence. For most, the active phase of dying ranges from 3 days to 2 weeks, though it may be hastened or prolonged based on individual circumstances (Murray et al., 2005). Trajectory of illness allows patients and families to attend to unfinished business while preparing for end of life. This preparation improves their quality of life and supports a dignified and peaceful death, which are the primary goals of palliative care (Murray et al., 2005). It is important for patients and their caregivers to gain a better understanding of illness trajectories to help them be in greater control of their situation (Murray et al., 2005).

According to the research review by Murray et al. (2005), three distinct illness trajectories were found to exist for people with progressive chronic illness. The first trajectory is a short period of evident reasonable decline over a few weeks or months requiring assistance for care. The second trajectory is long term limitations with intermittent serious episodes and deterioration generally associated with admission to the hospital and intensive treatment. The third trajectory is long term deterioration from a

progressive disability at an already low baseline of cognitive function from a previous significant illness. The authors noted the trajectories help to highlight the need to optimize quality of life in a dignified manner through the use of palliative end of life care (Murray et al., 2005). The use of end of life trajectories assists to establish a realistic dialogue among the health care team, patient, and caregivers to support quality of life and symptom management at an earlier stage in the disease progression. However, the authors found limitations with the use of categorizing patients in the slotted trajectory without regular review of patient status as patients tended to move through the trajectory at different stages along the care continuum. Murray et al. (2005) concluded that to care well for those who will be dying in the near future requires an understanding of how they may die and then planning appropriately for a ‘good death.’

Benefits of Early Palliative Care in EOL Care

Brumley, Enguindanos, and Cherin (2003) evaluated the effectiveness of a home based program for palliative care for end of life. This program evaluation using a comparison group study approach surveyed the satisfaction of 558 patients who participated in a 2-year community based palliative care (CPC) program at 60 days after enrollment. The three hundred patients who died during the study were selected for analysis. The 160 patients who received the intervention of CPC were compared to the 140 receiving usual care with no CPC supports. Both patient satisfaction and cost were positively impacted by the CPC intervention. Patients surveyed at 60 days after CPC enrollment reported improved satisfaction with care received, had fewer emergent care needs, hospital admissions, and skilled nursing facility stays compared with those who received usual care with no CPC support which led to a 45% reduction in medical

treatment related costs (Brumley et al., 2003). In addition, patients who were enrolled in the CPC program were more likely to die at home.

Thoonson, Groot, Engels, Prins, Verhagen, Galesloot, ... and Vissers (2016) described the planning of a study to evaluate if proactive early palliative care planning for patients at end of life would impact on patient and provider outcomes in the Netherlands. A randomized controlled study was described with a sample size of 96 patients in each of two groups. In the intervention group, care was coordinated by general practitioner physicians who participated in a five-hour training course, a coaching session, and two peer sessions at eight and ten months following the initial training focused on early identification of palliative care patients and proactive care planning. In the control group, care was coordinated by general practitioner physicians who provided routine care and did not participate in education, coaching, or peer review sessions.

In this study, semi-structured interviews and focus groups were used to assess if the education, coaching sessions, and peer sessions interventions related to earlier recognition and communication with patients that were nearing the palliative phase of chronic illness management were impacted upon outcomes for patients and providers. Six consultants and nine general practitioners constituted the sample for the study. The majority of those in the intervention group participating stated that they made changes in thinking and behavior regarding early identification of palliative care in patients that would lead to proactive care planning and identification of best practices. The authors concluded that the intervention was effective for the participating providers and that expanding early palliative care more to those with chronic conditions, particularly

congestive heart failure and chronic obstructive pulmonary disease, should be implemented (Thoonson et al., 2016).

Advanced Care Planning

A descriptive exploratory study by Heyland, Dodek, Rocker, Groll, Gafni, Pichora,...and Lam (2006) described what seriously ill patients and their family members consider to be the key elements of quality end of life care. A cross sectional survey was conducted at five tertiary care teaching hospitals across the country. Patient population eligibility criteria for the study included having advanced illness with a 50% probability of survival at 6 months or less at age 55 or older. The study included 28 elements that were administered via a questionnaire to patients. Elements noted as extremely important by study participants included: having trust in their healthcare providers; not being kept on life support when there is little hope for meaningful recovery; healthcare providers communicating information about prognosis and disease progression in an honest way, and completing important tasks and preparing for end of life (Heyland et al., 2006). The study concluded that variation exists among people's thoughts and wishes regarding end of life care which indicated the need for customized and individualized approaches to providing end of life care through advanced care planning (Heyland et al., 2006).

Serious Illness Care Goals

According to Kobewka, Ronksley, McIssic, Mulpuru, and Forster (2017), a substantial number of patients have poor symptom control near the time leading up to death which can cause great distress and pain. A retrospective cohort study by Kobewka et al. (2017) was conducted with 1065 adult inpatient beds which included patients that died in a three-month period. This convenience sample excluded people who died in the

emergency department before admission. The target of this study was to maximize the impact palliative care services can offer patients and their families. During the study period 14,266 patients were admitted to the hospital which resulted in 480 in-patient deaths. The authors found that almost one in nine patients who died in the hospital had two or more episodes of distress symptoms in the final 48 hours of life. Patients were more likely to have an order for no resuscitation written in their charts within 24 hours of admission than to have previous conversations about their end of life care wishes.

Kobewka et al. (2017) found that this high incidence of symptoms in patients with high comorbidity who have asked for less aggressive care suggested that further work is needed to integrate palliative care approach into chronic disease care.

Communication Barriers to End of Life Care

A mixed methods study by Periyanoil, Neri and Kraemer (2015) of multi-specialty providers caring for diverse and seriously ill patients in two large training medical centers conducted from 2010-2012 about provider reported barriers to end of life care communication discussed the concept of care versus cure conflicts. The study was undertaken to identify any barriers faced by providers in conducting EOL care conversations and to explore if provider age, gender, ethnicity, and medical specialty influenced the outcomes (Periyanakoil et al., 2015). The study by Periyanakoil et al. (2015) was conducted using an online questionnaire with no personal health identifiers collected to promote confidentiality and honest responses without concern for individual scrutiny.

The study noted that communication tendencies of providers and tensions to have these important conversations at EOL pointed to challenges with provider comfort level

in having EOL conversations. The study indicated that often these EOL conversations do not occur until an emergent need to do so occurs which leads to lost opportunities for getting the patient and family perspectives much earlier on in the disease process (Periyankoil et al., 2015). This research explored the provider connection between personal and professional beliefs/values and how to understand and communicate about EOL care with patients and families (Periyakoil et al., 2015). Results showed that 1040 of 1234 (84.3%) potential provider subjects participated with only 0.01% of providers reporting no barriers to conducting EOL conversations with patients. Ninety-nine percent of providers reported barriers with 85.7% of attempted conversations thus demonstrating that they found it challenging to have these conversations, especially if patient ethnicity was different from their own (Periyankoil et al., 2015). No significant differences were noted by gender or age, but younger providers reported that patient/family's limited health literacy was a bigger barrier to older providers in the sample as compared with younger providers. Top barriers identified for EOL conversation challenges included: language and medical interpretation issues; patient/family religious beliefs about death and dying; provider's varied views of patients' cultural beliefs, values and practices; cultural differences in truth handling and decision making; patient/family's limited health literacy; and patient /family's mistrust of providers and health care system.

This research indicates that stress about this sensitive subject makes having these conversations become more convoluted. Provider personal barriers to these essential conversations are problematic to the mission to promote quality of life. When EOL care conversations are avoided, these identified barriers often lead to missed opportunities that impact the ability to guide care and honor patient/family wishes and values.

Provider Issues Regarding EOL Care Discussions

A qualitative study by Green, Jerzmanowskam, Green, and Lobb (2018) explored provider experiences when providing EOL care to patients from culturally and linguistically diverse (CALD) backgrounds. Four focus groups were held with team members who worked in a palliative care unit in an Australian metropolitan hospital setting. Focus group members consisting of medical, allied health and nursing staff who worked in the palliative care unit were recruited as participants. Twenty-eight multi-disciplinary inpatient and community palliative providers participated in the study. The sample included doctors, nurses, social workers, pastoral care workers and physical and occupational therapists.

During the focus groups, moderators used a topic guide and open-ended questions to prompt in-depth group discussion. Topic areas included care/support issues for patients, communication issues, use of professional interpreters, concern about food, hydration, medications and cultural and spiritual needs. Barriers identified by providers included diverse language, ethnic background, nationality, dress, traditions, food, societal structures, religious characteristics, and quality of life views. Green et al. (2018) illustrated that respect for patient preferences and views is one of the major ethical principles supporting current palliative care in Western countries. Other important obstacles noted were communication, patient health literacy, and language which were identified as significant barriers to effective EOL care discussions and plans of care (Green et al., 2018).

Approaches to pain management were also reported as a significant challenge for providers where stoicism could play a role in treating a patient with strong opinions about

use of opioids and taboo discussions about death (Green et al., 2018). Preferences for care in the home setting, place of death, and use of complementary medicine during the EOL process were other areas of conflict among providers and patient/family's (Green et al., 2018). A predominant theme regarding provider experience caring for patients from CALD backgrounds was that death is difficult in any language, and concerns about approaching EOL was universal for all people (Green et al., 2018). Six key sub-themes emerged from the focus group results: determining the rules of engagement of diagnosis and prognosis; navigating the challenge of language to patient understanding; understanding migration experiences to establish trust; maintaining a balance between patient safety and comfort care; providing a good experience going into death through accommodation of beliefs; and navigating the important role of family members while privileging patient preferences.

Moral tension about professional concerns for patients understanding their conditions and family preference for non-disclosure of end stage illness to patients were also recognized by the authors. Providers acknowledged that non-disclosure to a patient was implemented from a wish to protect patients from emotional distress, but this led providers to have to continuously re-adjust their communication methods. Fear of death and associated taboos about dying process are primary issues for providers to navigate through communication challenges (Green et al., 2018). It was also identified that a lack of provider training about how to manage moral distress related to conflict between models of care and competing values equaled an ethical dilemma (Green et al., 2018).

Theoretical Framework

The theoretical framework that was used to guide this research is the Conceptual Model of Care for Improving End-of-Life Communication and Decision Making by Sinuff et al. (2015). The aim of using the Conceptual Model of Care for this research was to identify barriers to EOL care discussions, and identify areas for improvement and promotion of ACP and serious illness decision making throughout the disease process.

The model is depicted below:

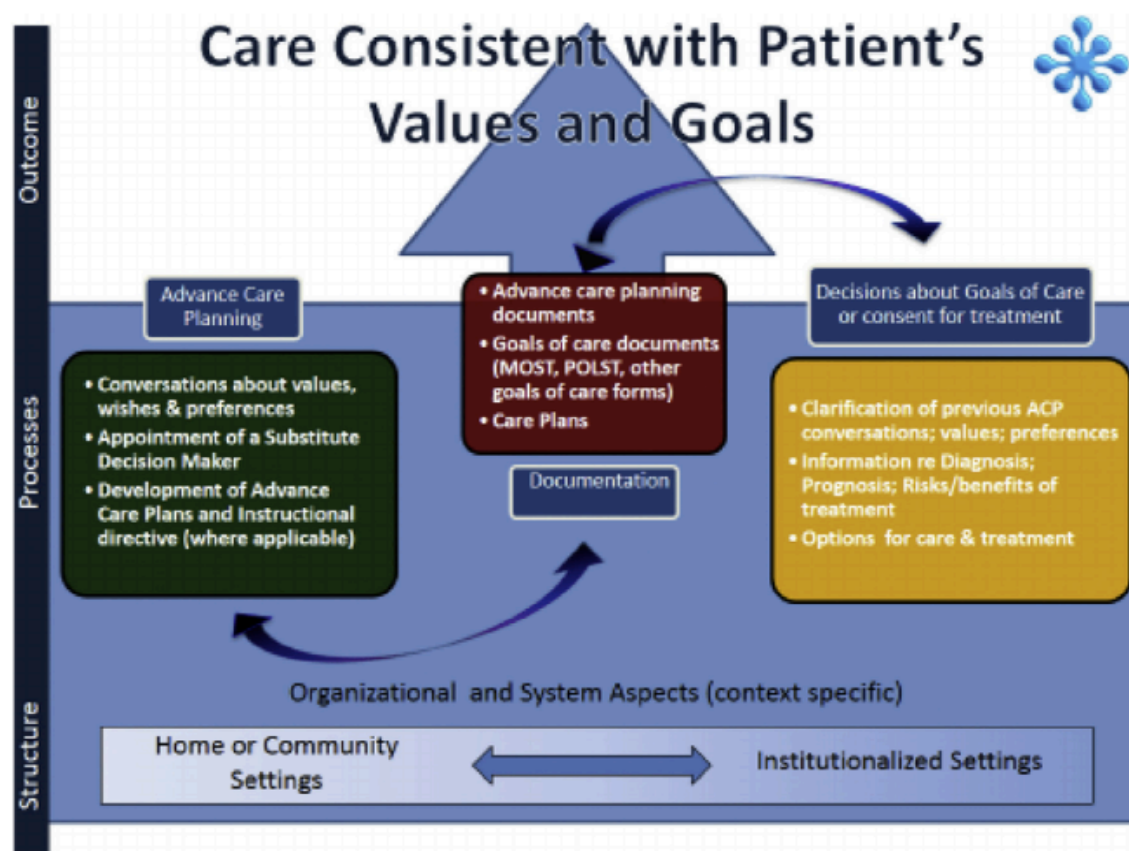


Figure 1. Conceptual model of care framework for improving EOL communication and decision making, (Sinuff et al., 2015).

End of life care and advance care planning are vital components of end stage chronic disease. The conceptual framework for improving end of life communication and decision making by Sinuff et al. (2015) identified key factors needed to help healthcare providers understand barriers to making change for EOL conversations and ACP and how to develop strategies to address them. This model contributes to developing care consistent with patient's values and goals. Sinuff et al. (2015) identified the use of this model to promote ACP leading to conversations and decisions about goals of care and options for care and treatment. Identifying the barriers faced by the NCM's about having discussions with patients about these sensitive topics can lead to healthcare change. The framework can be used to develop curriculum and expand education among healthcare providers about the importance of having earlier conversations about ACP and EOL care within primary care provider and community settings.

The Institute of Medicine (IOM) report *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* called for educational programs that aim to improve general awareness about death and dying, but also to encourage advance care planning and resources for physical, emotional, spiritual, and practical caring at the end of life (IOM, 2014). Studying the community perspective for EOL care is important to understand the impact of serious illness, dying, caregiving, grieving and death on individuals and families left behind (Sinuff et al., 2015). While medical care and health services are a significant part of the community, more changes are needed to support the end stage illness patient through the dying process. Developing a conceptual framework for the end of life process support systems that include workplaces, religious congregations, and the medical community to ease emotional, financial, and practical

burdens experienced by dying patients and their families is essential for change to routine practice in the primary care setting (Sinuff et al., 2015). Use of a conceptual framework on an organizational and systems level for community support will improve quality of care while leading the way for further development of evidence based practice (EBP) for expansion of these services so more people can benefit. The Conceptual Model of Care for improving EOL communication and decision making provides a basis for effective interventions and sustained support for improved quality of life to improve the patient and family health care experience with end of life process. The framework could also be the basis to support the development of policies, processes and procedures into the primary care practice setting to assist in standardizing ACP discussions at office visits. The main goal of EOL communication and decision making is to create a shared understanding about a person's values and care preferences that will lead to a plan of care in line with the patients' belief system.

Method

The purpose of this project was to identify perceived barriers to discussions around end of life advanced care planning conversations for nurse care managers working with patients with chronic disease in the patient centered medical home (PCMH) primary care physician practices in Rhode Island community settings. This quality improvement project explored what nurse care managers perceive as barriers to discussing end of life advanced care planning and asked their suggestions for decreasing these barriers.

NCM's who provide case management services for patients being served by a Rhode Island Accountable Care Organization (ACO) were the sample for this project. Inclusion criteria identified registered nurses who were English speaking, worked for the ACO as an NCM, were employed as an NCM more than 12 months, and who had experience working with patients through the life trajectory with advancing chronic illness. The project director presented the focus group project to the NCM's at the ACO to recruit volunteers to participate.

Rhode Island College Institutional Review Board reviewed the proposal and determined it was a quality improvement project. A letter of approval was obtained from Rhode Island Primary Care Physicians Corporation supporting the master's project focus groups allowing their nurse care managers to be recruited to participate (Appendix A). Recruitment letters explaining the focus group and topic were sent to the NCM work site and distributed by the Chief Nursing Officer (Appendix B). In total, six participants were recruited for the focus group and the same six NCM's were present at both focus groups that were conducted.

The project director conducted two in-person focus groups in December 2018. The first focus group held on December 6, 2018 was focused on potential barriers to end

of life care discussions (Appendix C). The second focus group held on December 13, 2018 was focused on solution to help end of life care discussions become part of routine care (Appendix D). The focus groups were held one week apart, each lasting 45 minutes in length, and were conducted onsite in the NCM work setting in a private conference room. Both focus groups were recorded with NCM comments summarized by the project director and sent to participants for consensus to assure the accuracy of information collected. NCM's verbally shared that they were in agreement with the collected and summarized information. Privacy of participants was maintained by excluding names and identifying information of the voluntary participants.

Results

A total of six nurse care managers participated in this quality improvement project. At the time of the focus groups, the participants who were registered nurses had been working as NCM's at Rhode Island Primary Care Physician Corporation. All six participants were female. No other participant demographic information was collected. The same six nurse care managers attended both the focus groups. The participants appeared engaged in the discussion and readily offered their feedback about what they perceived as barriers to end of life care discussions within the primary care settings. Each participant offered their thoughts on the focus group subject and participated in the discussion. The attendees reported that they had recently attended a palliative care and ACP course and had a lot of information to share as they believed this was an important topic to address.

The focus group discussions were recorded and quotes transcribed. The results were analyzed for each of the two focus groups by the project director. The results for the first focus group aimed at eliciting perceptions of barriers to end of life decisions were categorized into three areas: patient/family factors, organizational factors, and provider related factors.

The NCM focus group reported that patients and families were often in denial or were unwilling to discuss ACP. They stated that families expressed fear related to having these discussions with their provider or family. Other NCM's related that they had experienced barriers when patients and families were reluctant to "deal with" their own mortality. As a consequence of deferring these conversations, one NCM stated that "not discussing EOL can contribute to patient anger about care when they have not discussed their status with their family or provider." The NCM's also identified that avoided

conversations lead patients to be “surprised that their disease is so advanced and nearing EOL.” During the focus group the NCM’s discussed that this lack of communication does not allow the patient to be aware of important information that may have been intentionally withheld per family request and that the patient has a right to be informed of as illness progresses.

Another aspect of patient/family related factors identified by the focus group was that conflicts occurred when families asked providers not to tell the patient about end of life issues. They stated that this is often an ethical concern even though families are usually coming from a “good place” of wanting to protect the patient from knowledge that may be distressing to them. Providers being asked to keep deteriorating condition information from patients per family requests also present some ethical challenges with provider responsibility for veracity. The NCM’s reported that they believed that if the patient is not told about their status, the patient does not have the option to express their own choices or decide how they may want to spend their remaining time.

Another patient/family factor reported by the NCM’s was that they have seen many patients who believe that completing their end of life wishes or advanced directives is costly. The NCM’s reported that patients often postpone the process of completing documents such as Durable Power of Attorney (DPOA) or Living Will because of this misconception. Also, since many patients have not been previously asked about these documents, most people do not have advanced directives, know about them, nor have they shared their wishes with their family or provider.

The second category identified from the first NCM focus group was organizational factors. The NCM’s reported that the primary care practices that the

NCM's practiced in presented some barriers to end of life discussions with patients. In terms of role, the NCM's reported that the primary care practices did not demonstrate an awareness of the organization's role in facilitating these important discussions. The NCM's gave the example of the organizations' medical records not set up to ask for emergency contacts or if there are any ACP documents patients may already have. In addition, the NCM's reported that space for private and emotional conversations is limited. Another organizational barrier identified was that due to other provider demands, there is limited time to discuss EOL/ACP with patients.

The third category identified from the first NCM focus group was provider related barriers. NCM's stated that many providers are often uncomfortable or unwilling to have ACP discussions with patients and families. The NCM's also reported that providers "wait too long" to engage a patient in conversations about code status and care preferences. This results in it often being too late to implement these preferences. The NCM's identified a lack of provider understanding about what palliative and hospice care really is. They also reported that some providers do not support palliative care and hospice as part of their practice. They stated that the providers believe that if they were to suggest palliative care or hospice that they are giving up on their role of trying to heal or cure the patient. The NCM's reported that providers are often delegating EOL/ACP conversations to the NCM sometimes without introducing the topic themselves first.

The NCM's reported that because of all of these barriers, EOL care discussions started too late, patients were often caught off guard with abrupt end stage conversations that should have occurred much earlier in the process. The NCM's noted that starting conversations too late does not provide enough time for patients to benefit from EOL care

discussions. The first focus group content discussion was sent via email for review to all participating NCM's. No additional changes were provided and the NCM's verbally shared acceptance of the focus group discussion content.

The same six NCM's returned to participate in the second focus group held one week later to discuss perceptions about potential solutions to the previously identified barriers to ACP conversations. The participants all engaged in discussion and demonstrated interest in the issue. The results for the second focus group were categorized by the project director into two areas: patient/ provider related solutions and organizational related solutions.

The NCM's stated that they were in favor of promoting necessary changes in the primary care setting in order to normalize EOL/ACP conversations throughout the lifespan and disease trajectory. They also identified that adding these important conversation components to NCM individual and group teaching on chronic illnesses such as diabetes mellitus and congestive heart failure would assist in getting more patients exposed to these kinds of conversations about ACP. Another suggestion offered by the NCM's was to make it common practice at all provider visits to ask about ACP so that it would become less awkward for both the provider and for the patient and family. The NCM's suggested that reviewing patients' wishes at least yearly with their provider at the annual physical appointment would be a manageable change in primary care practice. The NCM's stated that those with chronic illness should have the issue addressed more frequently as exacerbation and deterioration of health occurs. The NCM's reported that it is important to take the stigma out of EOL conversations by normalizing it through open discussion about the patient's condition, through discussion

of what to expect, and through exploration of patients' values and beliefs. The NCM's also reported that they believed that with a generational shift, the younger population was more open to change. They stated that it would be beneficial to use this opportunity to initiate early conversations with this population so that the topic is normalized and wishes are noted in the electronic health record ahead of an emergent situation.

Provider related challenges were discussed by the NCM's. They reported being supportive of providers leading the way by completing their own advance directives. They believed that this would be an experiential learning activity that would allow providers a "hands-on" experience with ACP. They reported believing that this would allow providers to relate from personal experience to their patients on how to have these ACP/EOL care discussions and how to make their wishes known. The NCM's also noted that providers learning more about options and being change agents in practice transformation was key to successful change. The second focus group discussion content was also verified for accuracy with the six NCM's and no additions or changes were proposed.

The organizational solutions that were identified by the second NCM focus group included that the organization making EOL care discussions a quality measure would have the most impact on practice transformation. NCM's also noted that training all office staff to support this culture change and making it a routine practice to educate patients about the EOL documents available would be important to promoting ACP for patients. The NCM's supported facilitating small changes in each practice to grow over time similar to how existing programs such as the Diabetes Management initiative in primary care was implemented.

Summary and Conclusions

Limitations

One limitation to this quality improvement project is the small sample size of the NCM's who participated in the focus group and that they were selected from one primary care provider group in a single region of the country. In addition, the populations served by this provider group were mainly upper middle class with little representation of minority and low socio-economic status (SES) communities. Due to the fact that the focus group participants were mainly Caucasian women who work with middle to high SES patients who mostly live in suburban areas, future research should be done to include more diverse minority and low SES populations who live in urban areas.

Summary

The purpose of this quality improvement project was to identify barriers of NCM's to discussions about end of life care with patients in their clinical practice. The same six NCM's participated in two focus groups, the first to identify perceived barriers for end of life care and the second to identify potential solutions to those barriers. The barriers identified included: patient/family factors, organizational factors, and provider related factors. NCM solutions identified included patient related interventions such as normalizing and routinizing EOL/ACP discussion reviewing choices for all adults annually. Primary care practice transformation would benefit to be changed from a health care operational systems standpoint through the development of an EOL quality measure at the both the national and state levels through the Centers for Medicare and Medicaid. Other stakeholders to driving change would be from organizations like the National Committee for Quality Assurance (NCQA) who set forth Healthcare Effectiveness Data and Information Set (HEDIS) measures as standards of care for providers to follow in

order to obtain accreditation. Quality measures supported as health care policy for ACP could be used to improve patient centered health care in the primary care setting.

Conclusions

The findings of this quality improvement project showed that significant patient/family, organizational, and provider related barriers exist that impede end of life care discussion opportunities for patients and families. Changes that promote a culture shift towards ACP as a routine part of standard care are required. Health care providers need to be open to change at the practice level working in collaboration with the NCM to promote advanced care planning to be integrated into routine practice in the primary care setting.

Recommendations and Implications for Advanced Nursing Practice

The Robert Wood Johnson (RWJ) Foundation stated in *Catalysts for Change: Harnessing the Power of Nurses to Build Population Health in the 21st Century* that “Nurses are uniquely suited to play a significant role in building the best possible health and well-being for all in our nation” (RWJ, 2017, p. 2). This charge includes promoting an optimal end of life experience with adherence to the wishes of the patient as paramount. Advanced practice public health nurses can work with NCM’s to gain a unique perspective to identified barriers that can contribute significantly to improving the current end of life process on a local and national level through initiating practice, education, policy, and research focused on this issue.

In the clinical setting, advance practice nurses could develop programs to identify, educate, and support “provider champions” who could provide leadership within the ACO’s to promote change and normalize ACP conversations. Part of this program would include measurement and tracking of the implementation of ACP and incorporation of this as a quality measure which providers would be accountable for within the organization. APRN’s would be part of the quality team that incentivizes adherence to this program.

Incorporating ACP and EOL care into nursing education on the graduate and undergraduate level is critical to the plan to normalize these conversations as part of routine care. In addition, providing continuing education to practicing nurses including experiential learning with role play and case studies should be undertaken by APRN’s to increase skill and confidence of nurses and nurse care managers in direct care roles. APRN’s should promote end of life care education being required for accreditation for nursing and physician educational degree programs. They should also advocate for it to

be a requirement for continuing education for licensure similar to the opiate requirement in Rhode Island for nurses currently in effect.

Expanding education and outreach to all health care settings and to all types of healthcare workers is vital so the message about importance of ACP is a standard of care. In addition to educating nurses, a competency training requirement for all providers who are having this important end of life care discussions should be required. APRN's educating and leading others in this initiative is a significant role opportunity. APRN's can be instrumental in developing partnerships and leading change through collaboration with intraprofessional healthcare teams to improve the end of life standard of care. Linking the best practices to the community and other settings allows more stakeholders to become involved to improve end of life care outcomes for patients and families. Collaborating with the intraprofessional healthcare team including medicine, pharmacy and social work as well as community partners such as departments of health, religious groups, and other key stakeholders is an essential component for ACP sustainability. Examples of this type of partnership might be the development of an intraprofessional train the trainer program or a large scale multi-institutional intraprofessional simulation focused on ACP and EOL care.

Education of the public in ACP and EOL care is another key APRN role. General public awareness should be promoted through department of health educational and mass marketing campaigns including that the completion can be done without cost to the patient. Increased access to advance directive forms including digital and printed copies should also be made available to the public. Continued community outreach and classes at senior centers, libraries, and primary care practices should be ongoing to engage

consumers. Advocacy for the general public to be educated about ACP and normalizing discussions at earlier ages to continue through the lifespan is another goal to improve end of life care going forward.

APRN's should act as change agents to influence policy, legislation, and funding that impact ACP and EOL care on the local and national level as well as within organizations. This can be done through leadership activities such as lobbying, testifying, serving on boards, and initiating or supporting grass roots groups that serve as advocates for patient and families. Advocacy for ethical issues of equity to assure that the opportunity for access to advance care planning and end of life decision making are available to all segments of the population is another APRN role that is critical to this important goal.

Qualitative, quantitative, and mixed method research regarding ACP and EOL care including large scale epidemiological studies of the impact of education and policy change on patient outcomes should be conducted by APRN's. APRN's through leadership in practice, policy, and research as well as through engagement in the education of nurses, healthcare professionals, and the public can impact upon population health and the health of patients at end of life in a critical and meaningful way.

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Appendices

Appendix A – Project Agreement Letter from the ACO



Rhode Island College
Institutional Research Board
600 Mount Pleasant Avenue
Providence, RI 02908

October 12, 2018

To whom it may concern,

This letter is provided as agreement to serve as a collaborating agency on Karen Bouchard's master's major quality improvement project titled *"Perceived Barriers to Discussing End of Life Care Planning."* The project will involve project promotion, participant recruitment of nurse care managers (NCMs) within the organization, and two 30-40 minute focus group meetings with 4-6 NCs within Rhode Island Primary Care Physicians Corporation (RIPCPC). The student will be supported in completing her project with access to NCMs and space available for the two focus group meetings. RIPCPC is willing to facilitate Karen's work and looks forward to the project outcomes.

Sincerely,

A handwritten signature in cursive script that reads "Andrea Galgay".

Andrea Galgay
Director of ACO Development

Appendix B – NCM Project Recruitment Letter

Dear Nurse Care Manager,

You are being asked to participate in a quality improvement project entitled “Perceived barriers for discussing end of life care planning”. The purpose of this project is to identify barriers that nurse care managers face when discussing end of life care with patients during their clinical practice. The concept of end of life care discussions are currently not part of current routine care. The project will involve focus groups with NCM's to identify the perceived barriers that they experience in discussing end of life care to promote advanced care planning.

Your participation in this focus group will take approximately 30 minutes of your time for each of two focus group meetings. If you choose to be a participant in this, you will be asked to sit down to discuss your thoughts on this topic in a group setting of your peers. During the focus group, the focus group leader will write down and record notes and tape your responses as you provide feedback. Shortly after each focus group meeting, the project director will provide you with a summary of the key points of the discussion to assure that comments are correctly represented. If you agree to participate, you will be interviewed at the Rhode Island Primary Care Physicians Corporation office.

Your completion of this will not benefit you personally. You will receive no compensation. Participation is voluntary and not required by your employer Rhode Island Primary Care Physicians Corporation. There will be no negative consequences to declining participation in this project. Also, you can change your mind about participating at any time without negative consequences.

We are hoping these completed focus groups will provide information to help provide better insight into the perceived barriers that nurse care managers encounter in the primary care setting in regards to end of life care discussions. The completed focus group data will be kept confidential. None of the information you provide will have your name or any identifying information on it that will identify you personally. Records will be kept in a secure file, and access will be limited to the researcher. All data will be kept for a minimum of three years, after which it will be destroyed.

If you have any questions about this research study, you may contact the Karen Bouchard, RN or Principal Investigator, Carolyn Wood, PhD, RN at (401) 258-3223. Please respond to this Email if you are interested in participating in this quality improvement project.

Thank you,

Project Director

Karen Bouchard, RN BSN CCM

Appendix C – Focus Group 1 Discussion Notes

December 6, 2018

Question- What do you perceive as barriers to end of life care discussions?

Nurse Care Manager quotes:

- “Limited time to discuss EOL/ACP with patients”.
- “Physician uncomfortable or unwilling”.
- “Physician lack of understanding about what Palliative and Hospice care really is”.
- “Practice not identifying their role in these important discussions, not asking for an emergency contact, or what wishes or documents a patient may already have”.
- “Starting conversations too late, not enough time for patients to benefit from care discussions”.
- “Deflecting EOL/ACP conversations to NCM, sometimes not even introducing the topic first”.
- “NCM's are having EOL conversations more than physicians do”.
- “Patient in denial or unwilling to discuss”.
- “Some physicians do not support Palliative/Hospice as part of practice; feel like they are giving up trying to heal someone”.
- “Space for private and emotional conversations is limited”.
- “Avoided conversations lead patients to be shocked that their disease is so advanced and nearing EOL”.
- “Not discussing EOL can contribute to patient anger about care, information may have been kept from them, have a right to be informed as illness progresses”.

- “Patients may feel robbed of time without EOL knowledge may not get to make decisions about care choices or how they will spend remaining time”.
- “Physicians wait too long to engage a patient in conversations about code status and care preferences, often too late”.
- “Since they have not been asked most people do not have advanced directives, know about them nor have shared their wishes with provider “.
- “Many people believe filling out wishes or advanced directives are costly and postpone completing documents such as DPOA, Living Will...”.

Appendix D – Focus Group 2 Discussion Notes

December 13, 2018

Questions- What solutions do you have regarding for incorporating EOL care planning discussions in primary care?

NCM quotes:

- “Add these conversation components to NCM individual and group teaching on chronic illnesses such as DM, CHF, etc...”.
- “Make this common at all provider visits, will not be so awkward this way”.
- “Review patient’s wishes at least yearly with provider at annual physical appointment. Those with chronic illness can be addressed more frequently as exacerbation and deterioration of health occurs”.
- “Take the stigma out of EOL conversations by normalizing it through open discussion about patient condition, what to expect, patient values and beliefs”.
- “Generational shift is happening with younger population more open to change, use this opportunity to initiate early conversations so wishes are noted in EMR ahead of an emergent situation”.
- “Providers learning more about options and being change agents in practice transformation”.
- “Make EOL care discussions a quality measure”.
- “Have all office staff trained to support this culture change”.
- “Educate about the EOL documents available”.
- “Providers can lead the way by completing their own advance directives”.
- “Small changes in each practice will grow over time similar to Diabetes management initiative in primary care”.